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ABSTRACT

This report describes factors distinguishing rural families with special-needs children and their communities from those in non-rural settings. Rural communities have distinct environments and unique strengths and weaknesses, differing even among themselves. A diversity among rural lifestyles, values, resources, and other socio-cultural factors call for unique responses to the needs of rural special-needs children and their families. The involvement of families in rural programs is essential for success. Interagency cooperation is also important. Funding inadequacies, staff recruiting problems, transportation difficulties, professional isolation, staff development needs, support services, and local resistance to change are all hindrances to such family-community collaboration. Factors to be considered when designing a service-delivery system for rural disabled children include: population sparsity, topography, cultural diversity, language differences, economic lifestyles, students' ages and level of disability, history of services, available resources, cost efficiency, and governance systems. This document describes many successful working service-delivery models and strategies. Service-delivery strategies discussed include the use of (1) non-school personnel; (2) power and communications sources; and (3) responses to family needs. The document concludes that, while community characteristics may differ, planners may identify variables to design appropriate, individualized models meeting the needs of children, parents, communities, and service agencies. (TES)

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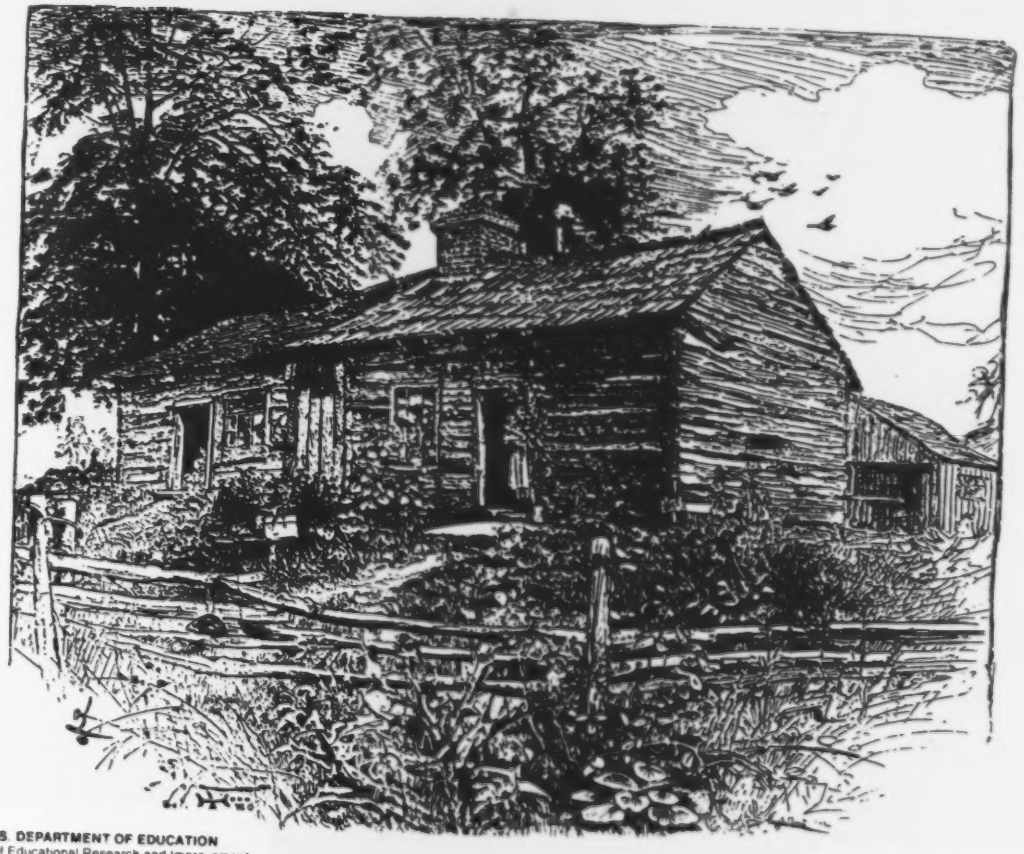

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RURAL FAMILY-COMMUNITY PARTNERSHIPS--
RESOURCES, STRATEGIES, AND MODELS

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ABSTRACT

This report describes factors distinguishing rural families with special needs children and their communities from those in non-rural settings. Rural lifestyles, values, and other social and cultural factors are described, as are the unique needs of rural families with special needs children. Resources needed for appropriate services, considerations for service delivery, and model development strategies are discussed. Sample strategies are outlined for serving children, increasing public awareness, and formulating rural family-professional partnerships.

RURAL FAMILY-COMMUNITY PARTNERSHIPS-- RESOURCES, STRATEGIES, AND MODELS

Introduction

The purpose of this monograph is to provide a description of factors distinguishing rural families with special needs children and their communities from those in non-rural settings. A brief description will be given of rural lifestyles, values, and other social and cultural factors. The unique needs of rural families with special needs children will be discussed, as will resources needed for appropriate services, considerations for service delivery, and model development strategies. Sample strategies will be given for serving children, increasing public awareness, formulating rural family-professional partnerships, and raising the self-esteem of those in rural communities seeking health care assistance.

The Uniqueness of the Rural Community Context

Rural communities have distinct environments and unique strengths and weaknesses. Many rural areas still have a relatively high trust factor, close family ties, and a "sense of community." Extended families are a resource to programs. Rural citizens typically evidence a willingness to volunteer and to help those with disabilities. Rural subcultures vary tremendously. They range geographically from remote islands and deserts to clustered communities, and economically from stable classic farm communities to depressed lower socioeconomic settings and high-growth "boom or bust" communities. The array of rural service programs ranges from isolated agencies or schools serving as few as one to ten children in a location 350 or 2,000 miles from the next nearest service agency, to programs located in small clustered towns or surrounded by other service agencies.

The problems of serving a cerebral palsied child in a remote area with no physical, occupational, or speech therapist, and where 250 miles exists between that child and the next cerebral palsied child, are quite different from problems encountered in a more clustered rural area, where the chief barrier to service delivery is administrative apathy.

Obviously, location has tremendous implications for proximity to resources, especially highly specialized services such as physical or occupational therapy.

Figure 1 on the following page may be helpful in conceptualizing the diversity of rural communities and service delivery systems (schools, health, mental health, and other services agencies). Each of the variables listed has individual ramifications for service delivery. For example, a rural school's administrative structure has implications for securing resources outside of the school. A district that is part of a cooperative can usually obtain the services of an occupational therapist more easily than can a single isolated district.

Two key variables of service delivery are *population density* (Are there an adequate number of children with a given disability so that a rural community or service agency can "afford" to hire a specialist?) and *topography* (Does a mountain with untraversable roads at certain times of the year inhibit transportation of services?). Interaction of these two dimensions with that of "other community and district variables" further individualizes an area and its services. Change of one variable in any of the three dimensions further differentiates a given community from others. Because this is an open model, the number of possible types of rural communities is infinite (...N). In fact, previous ACRES research cataloged over 300 combinations when conducting on-site visits (Helge, 1984). Thus, rural service delivery systems must be individually designed.

Table 1 (see pages 4-5) illustrates issues differentiating rural and urban communities as they serve children with disabilities.

Importance of Family Involvement and Rural Family-Community Partnerships

The involvement of families in educational programs for rural children with disabilities is essential for program success. Families are resources for program follow-through (particularly in summer months) and can supply new information useful to teachers and therapists. Parents and siblings, through involvement, develop more realistic expectations for childrens' achievement. Effective family communication systems increase

Figure 1

Dimensions of the diversity of rural community service delivery systems

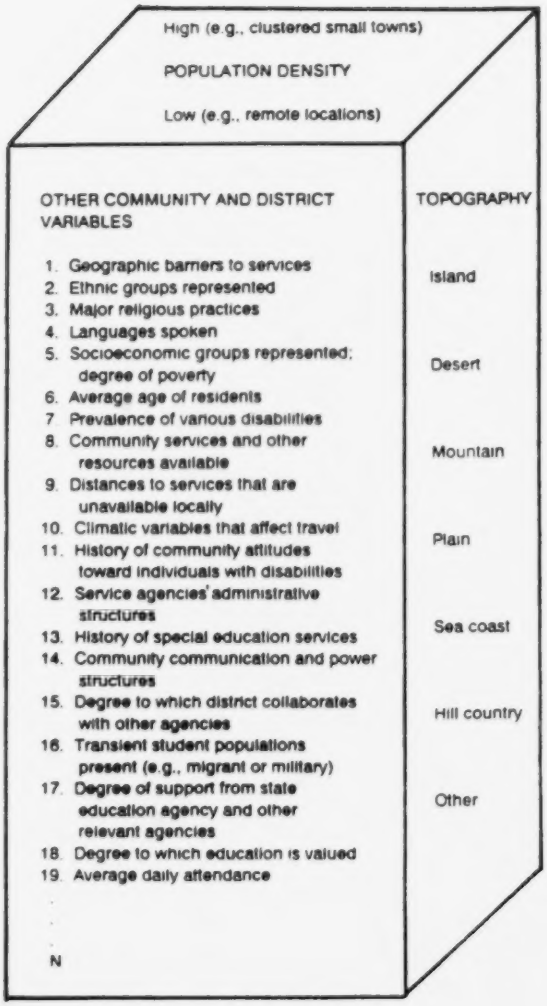

High (e.g., clustered small towns)
POPULATION DENSITY
Low (e.g., remote locations)
OTHER COMMUNITY AND DISTRICT VARIABLES
1. Geographic barriers to services
2. Ethnic groups represented
3. Major religious practices
4. Languages spoken
5. Socioeconomic groups represented; degree of poverty
6. Average age of residents
7. Prevalence of various disabilities
8. Community services and other resources available
9. Distances to services that are unavailable locally
10. Climatic variables that affect travel
11. History of community attitudes toward individuals with disabilities
12. Service agencies' administrative structures
13. History of special education services
14. Community communication and power structures
15. Degree to which district collaborates with other agencies
16. Transient student populations present (e.g., migrant or military)
17. Degree of support from state education agency and other relevant agencies
18. Degree to which education is valued
19. Average daily attendance
N
TOPOGRAPHY
Island
Desert
Mountain
Plain
Sea coast
Hill country
Other

TABLE 1
Issues Differentiating Rural and Urban Communities as They Serve Children with Disabilities

Issues	*Rural*	*Urban*
Transportation	Interagency collaboration hampered by long distances High costs Climatic and geographic barriers to travel	Problems primarily associated with desegregation issues or which agency or bureaucratic structure is to pay for transportation
Community structure	Sense of "community spirit" Personalized environment	Environment depersonalized except within inner-city pockets of distinctive ethnic groups
Geography	Problems include social and professional isolation, long distances from services, and geographic barriers	Problems posed by logistics of city (e.g., negotiating transportation transfers, particularly for wheelchairs)
Difficulties in serving specific disabilities	Low-incidence handicaps hardest to serve; integration of mildly/moderately handicapped students more acceptable than in urban schools	Adequate numbers of low-incidence handicapped children typically allow students to be clustered for services or for a specialist to be hired; urban environment frequently not attitudinally as conducive to acceptance of mainstreamed mildly/moderately handicapped students
Backlog of children for testing and placement	Results from lack of available services (specialized personnel, agency programs, funds, etc.)	Results from bureaucratic and organizational barriers
Communication	Mainly person to person	Formal systems (e.g., written memos) frequently used
Percent of school districts	Two-thirds (67%) classified as rural	One-third (33%) classified as metropolitan
Personnel turnover	Commonly 30% to 50% among specialized personnel such as speech, physical, and occupational therapists; especially serious among itinerant personnel serving low-incidence populations	More commonly involves program administrators; teacher turnover less than in rural schools
Student body composition	Small numbers of handicapped students in diverse ethnic and linguistic groups pose difficulties for establishing "programs" for bilingual or multicultural students Difficulties in serving migrant handicapped students because of low numbers and few appropriate resources Qualified bilingual and multicultural personnel difficult to recruit Appropriate materials and other resources typically unavailable or inappropriate Religious minorities frequently strong subcultures	Typically has a wide variety of ethnic and racial groups Open student populations pose challenge and service delivery complexities, but comprehensive multicultural programs are feasible

TABLE 1 (continued)
Issues Differentiating Rural and Urban Communities as They Serve Children with Disabilities

Issues	*Rural*	*Urban*
Approach of relevant professionals	Generalships needed to perform a variety of tasks and teach a variety of ages, handicapping conditions, and subjects	Specialists needed to serve as experts on one topic area or with one age group or disability
Educational service providers	Poor motivation; lack of educational goals and relatively low values for formal education	Discipline problems prevalent
Availability of technical resources	Advanced technologies less often available, particularly for student use	Modern technologies more prevalent than in rural schools and more available for use by students
Service provider qualifications	Agencies frequently forced to hire unqualified personnel (e.g., schools frequently use temporary certifications)	Service providers and educators more likely to have advanced degrees with an appropriate specialization
Personnel recruitment and retention problems	More serious than in urban areas related to low salary levels, social and professional isolation, lack of career ladders, long distances to travel, and conservatism of rural communities	Problems regarding some types of professionals, but less than in rural areas; discipline, crime violence, pollution, impact retention, etc.
Causes of funding and policy inequities	Rural "advocates" fewer in number and therefore less vocal; sparse populations facilitate policies ignoring rural problems	Separate but unequal services created by government policies and funding mechanisms facilitating areas with inadequate tax bases; existence of inner-city minority groups with little political clout facilitates unequal treatment for urban handicapped children

the level of support for special education and related services in the rural community. Typically, long-term relationships are established because many rural service providers are responsible for a handicapped child for more than one year at a time. Children usually feel more comfortable when there is a close working relationship between parents and service providers--both of whom they respect.

Interagency Collaboration in Rural Areas

Problems of organizing to deliver rural services relate to a basic attribute of rural districts--i.e., how to provide economical, specialized programs in sparsely populated rural areas. The cost per unit of specialized services is higher in rural areas than in urban areas due to fewer professional resources available, transportation barriers, and other rural attributes. Because of sparse populations, geographic barriers, related transportation problems, and few specialized resources available, it takes all possible agencies and family members to appropriately deliver services in rural areas. Rural agencies and families generally welcome opportunities to share information, funds, clients, staff, programs, facilities, and equipment in attempts to address severe gaps in service delivery systems.

Major problems regarding interagency collaboration in rural areas have stemmed from (1) difficulties ascertaining which program will provide or pay for a given service and under what conditions, (2) geographic and other barriers obstructing service access, and (3) inadequate resources available. Rarely in a rural area has the problem been duplication of services or competition between agencies.

A national study conducted by ACRES (Helge, 1981) indicated that the following needs must be met for effective interagency collaboration: clarification of each agency's role; developing an implementation plan for coordinating efforts; overcoming turf problems; obtaining resources to implement an interagency agreement (e.g., making that part of an individual's work responsibility); facilitating communication between local, federal, and regional agencies; transportation money to attend interagency meetings; and local awareness of community resources available. Rural early childhood service personnel

have, in the past, been the leaders in initiating interagency collaboration efforts. Their strategies have included selling concepts of early intervention to multidisciplinary groups, team planning, maintaining credibility and visibility with multiple agencies, engaging in trouble-shooting and negotiating, and initiating program follow up and continuity.

Problems Related to Rural Family-Community Partnerships

The following problems were identified in a number of national studies conducted by the American Council on Rural Special Education (Helge, 1984a,b; Helge, 1988). These factors frequently inhibit family-community involvement in rural areas.

* Children with disabilities are frequently not identified, particularly those with mild and moderate disabilities. This is partly because of the rural norm of "taking care of one's own." It is also because rural Americans inherently dislike the labeling of individuals.

* Rural service providers tend to "make do" when given inadequate resources. Their innovativeness is to be applauded. However, sometimes they settle for less.

* Rural schools and other agencies usually do not have enough enrollments of children with low-incidence disabilities to gain funding for segregated special education services or teaching specialists. They typically also have no other available services or support staff. Mainstreaming children who need major adjustments in classroom curricula, materials, or activities, may be particularly difficult for service providers serving large numbers of non-disabled children.

* Rural community mores and values are different from those of nonrural areas. Many rural family members are reluctant to become involved with schools and other agencies because they view professional personnel as authority figures.

* The penchant for independence that is characteristic of many rural families, contributes to a reluctance to depend on outside agencies. It is sometimes difficult for professionals to understand and approach them.

* Rural families operating farms may view problems as cyclical and expect them to change from year to year or season to season. This perspective can make it difficult for them to accept a chronic disability.

* Rural communities have much higher poverty levels than nonrural areas, and rural service agencies serve greater percentages of children with disabilities.

* Rural communities and schools contribute greater percentages of their local resources for education, medical, and social services. However, rural services cost more than similar services in urban areas because of expensive factors including transportation requirements and scarce

professional resources. Even though rural populations increased somewhat during the last decade, their tax bases did not. Consequently, many services have inadequate funding.

* The increasing economic problems of rural areas have greatly elevated family stress. Problems that in the past were rare (e.g., chronic depression, suicide, substance abuse, spouse or child abuse) are increasing rapidly. Poverty leads to further isolation of the family.

* Many rural parents are unaware of their rights and those of their children as per Public Law 94-142 and other requirements.

* Most rural communities lack family resources such as parent support groups or programs.

* Some professionals view parents as adversaries and fear the roles of parents as lobbyists for child rights.

* Vast distances between schools, agencies, and homes, sometimes combined with inclement weather or impassable roads, impede family and staff travel. Transportation is also expensive and time consuming for rural parents who must drive long distances so that their children can participate in a quality program.

* Adolescents leave home at unusually early ages in many rural areas. Parents may lack ownership or responsibility for such children and the children may lack successful role models.

* The expenses of medical attention and specialized equipment are almost insurmountable for most rural families. Hiring babysitters is almost impossible. (Babysitting can cost as much as $18.00 per hour for children with highly specialized needs.)

* Quality respite and daycare is frequently unavailable, and the constant strain of caring for a disabled child can cause families to break up.

* Lack of various types of qualified medical and educational specialists and difficulties recruiting and retaining such personnel present difficulties appropriately caring for at-risk infants, transitioning technology-dependent children back into the local community, and assuring continued service delivery.

* Low educational levels of many rural parents and lack of local area specialists inhibit follow-through concerning medical recommendations. Many parents in economically depressed areas have low motivation, suffer from alcoholism, or have other disabilities.

* Geographic isolation and population sparsity contribute to problems obtaining appropriate medical and social services.

* Revenue shortfalls, inflation, and other funding problems experienced by numerous states and impoverished rural communities have added to funding difficulties.

* Personnel recruitment and retention difficulties are a major problem. Standards for hiring rural personnel are typically lower than standards in nonrural areas. Emergency certifications are rampant.

* While rural service providers, including educators, applaud the national impetus towards excellence, certification guidelines are felt to be too specialized for rural programs (Helge, 1984a). Mandating that one or more areas of specialization occur in training is particularly difficult when most rural service providers work with a variety of low-incidence handicapping conditions and ages.

* Preservice training programs generally do not consider special rural needs and circumstances when designing training programs. Most trainees are not trained specifically to work with rural communities, parents, social groups, and communication and power systems.

* Particularly when community agency personnel work on a part-time basis with schools, unsatisfactory working conditions may include lack of an office or a consistent and quiet place to work with teachers, students, and their families.

* Itinerant staff are frequently faced with difficulties related to lines of accountability, long distances and times traveling, heavy caseloads, professional isolation, inadequate staff development, and inadequate communication with rural families.

To summarize, funding inadequacies, difficulties in recruiting and retaining qualified staff, geographic isolation, transportation difficulties, family involvement, professional isolation, needs for staff development, serving low-incidence disability populations, resistance to change, interagency collaboration, providing support services, and negative or lethargic attitudes of agency personnel and communities toward handicapped children, are significant problems in rural areas. These are compounded in areas of cultural and ethnic diversity, particularly when providers are serving transient populations such as migrant families.

Considerations for Service Delivery Planning

As rural communities are so diverse (see Figure 1), there is no one appropriate model for rural service delivery.

Just as urban models are not appropriate for rural communities, there is no "one" rural service delivery model for the great variety of rural subcultures. It simply cannot be assumed that a practice effective in remote Wyoming ranching territory will be viable on an

isolated island, in part of a cluster of New England seacoast towns, or in an agricultural migrant camp. Instead, service delivery models must be individually designed for the rural community and service delivery systems in which it will be implemented.

Each of the 15 factors discussed in the sections that follow must be considered by those designing a service delivery system for rural children with disabilities. Most importantly, the interrelationships between them must be assessed. For example, districts with equivalent population densities should plan in significantly different ways if one service delivery system is surrounded by mountains with relatively untraversable roads all winter, while the other is located in a flat agricultural area with mild winters.

Population Sparsity

The population per square mile is significant for the model planner. Although a rural area is by definition relatively sparsely populated, services must be planned in a dramatically different manner for small clustered townships than for schools located on remote islands, vast rangelands, or in the isolated bush villages of Alaska. This is important in determining whether students with similar learning needs are available to be clustered for services and in assessing proximity to services.

Distance From Child to Services Needed

Assuming a service exists, the planner needs to know the distance from child to service location or from itinerant staff member to child. Knowledge of the actual travel time will assist in determining whether a service or professional should be transported to the student or vice versa.

Geographic Barriers

Absolute distance from potential services to a student is frequently complicated by geographic barriers such as mountains, untraversable roads, or the necessity of taking ferries or small planes. In some areas of the Northeast and Northwest, roads do not exist. Personnel must either travel by light plane, ferry boat, or snowmobile, or even detour through Canada, to reach the rural service area. Because the U.S. government owns and

prohibits travel through large areas of several Western states, personnel in these states must frequently travel an extra 2 or 3 hours to reach their service destinations.

Climatic Barriers

In areas with severe climates or seasonal problems such as heavy spring flooding, it may be relatively unimportant (and highly frustrating) to planners that a qualified professional or program is located only an hour's distance from the child. Children with disabilities suffer when program continuity is frequently disrupted by weather-related problems. Administrators also experience difficulties with planning or implementing longitudinal goals for a child.

Language Spoken in the Community

Just as primary languages spoken by a handicapped child must be considered when designing an IEP, the primary language of the rural child and his or her family also has relevance for selecting appropriate personnel, especially itinerant staff who visit rural communities with lifestyles and cultures different from their own. It is also extremely important to the administrator who is considering clustering children for services.

Cultural Diversity

Besides the most readily recognized ethnic cultures with which service planners try not to interfere (knowing that disrupting family life interferes with the effectiveness of services), unique rural subcultures must be considered. Research has clearly indicated that some federal and state service requirements, though well intentioned, were written without extensive familiarity with various rural cultures. Implementing the requirement that written parental permission be obtained, for example, is particularly difficult in some rural-based cultures having no written language.

Similarly, some rural-based subcultures have no concept of the terminology of special education and related services (e.g., learning disabilities). Some religious cultural minorities also have beliefs and traditions that are at variance with school traditions, such as religious holidays that conflict with a school calendar of services. Planners must also be

aware of unique community and parent expectations for the success of handicapped children. Handicapped children who belong to transient rural subcultures (such as migrant and military populations), also provide unique challenges for the rural services planner. These include tracking children to ensure program continuity.

A relatively new phenomenon facing many rural planners is the "boom or bust" syndrome prevalent in states with a priority of developing energy resources. Some administrators, faced with "overnight" doubling of their client population because of temporary influxes of community workers, find that by the time they locate resources to provide services, their populations have significantly decreased.

Economic Lifestyles of the Community

Rural communities, particularly those with relatively nondiversified economies, tend to schedule their lives around the requirements they face as they attempt to make a living. Service delivery planners should be aware of total community priorities and events that might influence or even interfere with service delivery. Examples include handicapped children who are absent during periods of agricultural, fishing, or timber "harvesting" or during seasonal festivals in resort communities.

Community Communication and Power Structures

The service delivery planner who ignores the existing communication and power structures of a rural community will probably not be required to plan such services for an extended period of time. Typically, informal systems are more potent than those that are formally outlined. Informal rules often have significant ramifications for serving children with disabilities. For example, they may affect such issues as who, in reality, assigns duties to the itinerant specialist, confidentiality of data, and the person to whom service deliverers feel accountable.

Ages of Children Served

The planner should ascertain the ages of children to be served in the local program and in any adjacent communities or systems in which collaborative services are being

considered. America still has many service agencies in which one service provider is responsible for a wide range of ages. Studies have shown that such a situation entails a great deal of stress associated with burnout (Dickerson, 1980; Helge, 1984). Thus it behooves the administrator to attempt to group children in similar age groups if at all possible. Exceptions, of course, are made when developmental age is more critical than chronological age.

Type and Severity Levels of Disabilities

The level of severity of a disability frequently determines whether or not a child can receive services within a mainstreamed setting. Some types of handicapping conditions tend to be more prevalent in some rural subcultures than in others. Areas with colder temperatures tend to have more hearing-impaired children, and that areas of poverty as well as migrant cultures tend to have greater concentrations of mentally retarded children because of inadequate nutrition, health care, and prenatal care. Designing services for such unique groups of children requires specific actions by the planner (Helge, 1984).

History of Services Provided

Past services to handicapped children in a particular service area are closely linked not only to available funding and awareness of federal and state regulations, but also to community attitudes. In rural communities, key power sources (whether the judge, the school board chair, or the wealthy farmer who likes children and serves as a janitor during the off season) have pervasive influences on services.

Rural citizens are typically unimpressed by what they are told they "have to do" for handicapped children. In contrast, they are highly motivated to provide appropriate services when the initiative is theirs. Adept administrators understand and plan to use such inherent rural community attributes, particularly when attempting changes. In rural communities having a unique ethnic heritage, it is possible and important to plan new services that will be palatable to the native heritage and as much as possible preserve the community's self-determination and identify. It is not surprising that isolated rural

communities whose only choice in the past has been to send their disabled students to communities or cities with dissimilar cultures have resisted change--and sometimes even the concept of special services.

Currently Available Resources

While federal regulations require that appropriate services be available to each child in the "least restrictive environment," the law does not state how such services are to be delivered. Despite their reputation for inflexibility, rural citizens have, out of necessity, long tended to be creative problem-solvers. The model planner should assess all existing resources. The resulting catalog of current resources should include intra-school and external facilities, equipment, and so forth. The planner should then identify and take advantage of the "hidden" resources endemic to rural America such as its sense of volunteerism and community spirit.

Relationship of Governance Systems to External Resources

A district or other service agency that is administratively part of a cooperative or has access to a state's educational service district typically has greater resources available to it than does one where the majority of external resources must come from a centralized state education agency. This is particularly true when the isolated agency is located a great distance from the state headquarters or when geographic or climatic barriers exist.

Cost Efficiency

When feasible, the planner should assess costs of alternate systems of providing a given service. The fiscal realities of rural service delivery systems must be considered. However, the planner will typically not be faced with evaluating monetary trade-offs between equivalent alternatives. It is more likely that he or she will have to present a need and request funds from a supervisor, a cost-conscious rural board, or a community organization.

The administrator should be knowledgable of budgetary accountability systems. Data gathering and subsequent presentations should consider cost efficiency in light of a

varying range of potential effectiveness. The planner should address not only local expenditure per child vs. placement costs out of the area, but funding alternatives. The planner should also be prepared to answer questions concerning the percentage of the local school agency contribution for salaries, transportation, consultants, and equipment.

Expertise and Attitudes of Available Personnel

The planner must not only note the grade levels and types of disabilities that existing personnel are prepared to serve, but also their flexibility in serving as generalists (i.e., serving several types of disabilities) or as specialists. Formal as well as informal training must be considered, and attitudes of personnel toward serving children with various disabilities are equally important. The planner may need to structure staff development opportunities designed to guarantee that children are served by personnel who respect them and are comfortable with their specific disability.

Dealing with Interrelationships and Combinations of Factors

The importance of understanding and considering the interrelationship of all 15 of these factors cannot be overemphasized. Combinations of factors are critical and should be weighted more heavily than single-factor barriers to service delivery.

It is difficult to design an effective service delivery model when a rural agency has multiple cultures or when, for example, the disabled child resides in a sparsely populated area 150 miles from essential services. The task is even more difficult when the child's culture differs significantly from that of the nearest service area, when service delivery is inhibited by geographic or climatic barriers, or when the community's power structure has low expectations for the success of such a child.

The planner should identify which of the 15 variables are problematic, select those that appear to be most important, and address those variables first. Problems that can be quickly ameliorated (e.g., by linkage with technological or other resources available through the state or by gaining the understanding and support of the local power

structure), should be. Usually, the planner can merely acknowledge factors that are unchangeable "givens," such as spring flooding, when designing the service delivery plan.

Figure 2 on the following page illustrates the fact that planning becomes a more arduous task as the number of problematic factors increases. As one factor is combined with another and the planner spans out to each concentric circle of Figure 2, it is increasingly difficult to design an appropriate service model.

Model Development

After considering these factors, the planner is ready to develop a workable service delivery model. There is no such thing as a pure model for rural service delivery. Rather, eclectic approaches are the rule, and numerous variables must be juggled (such as cost vs. intensity of need or availability of alternate services).

Technological advances are greatly improving the options of the local rural agency. For example, it is no longer necessary to choose between hiring a specialist or a generalist if a generalist can use satellite instruction (or some other technology) to supply specialized instructional content.

Variables of a service delivery model that must be manipulated so that the resulting eclectic model has a "fit" are as follows:

Equipment
Facilities
Financial system
Staff development program
Transportation system
Staffing for services
Parent involvement and training
Community involvement and support
Governance system
Interagency collaboration

Figure 3 on page 18 illustrates the process of designing a rural service delivery model. Factors than can present planning problems but cannot be controlled by the model designer are termed "givens." Factors that can be manipulated by the planner are labeled "variables." The planner can create an appropriate service delivery model by recognizing givens and controlling variables.

Figure 2.

Increasing levels of difficulty in designing a service model.

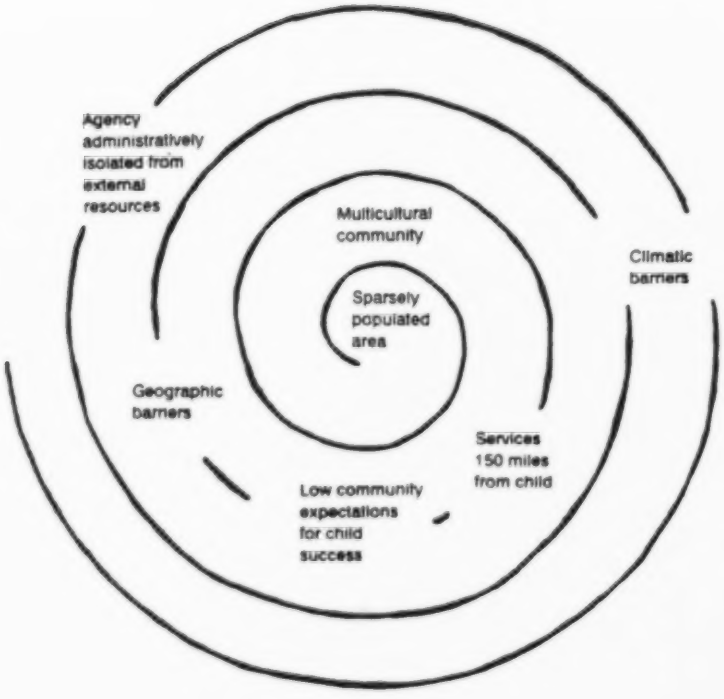
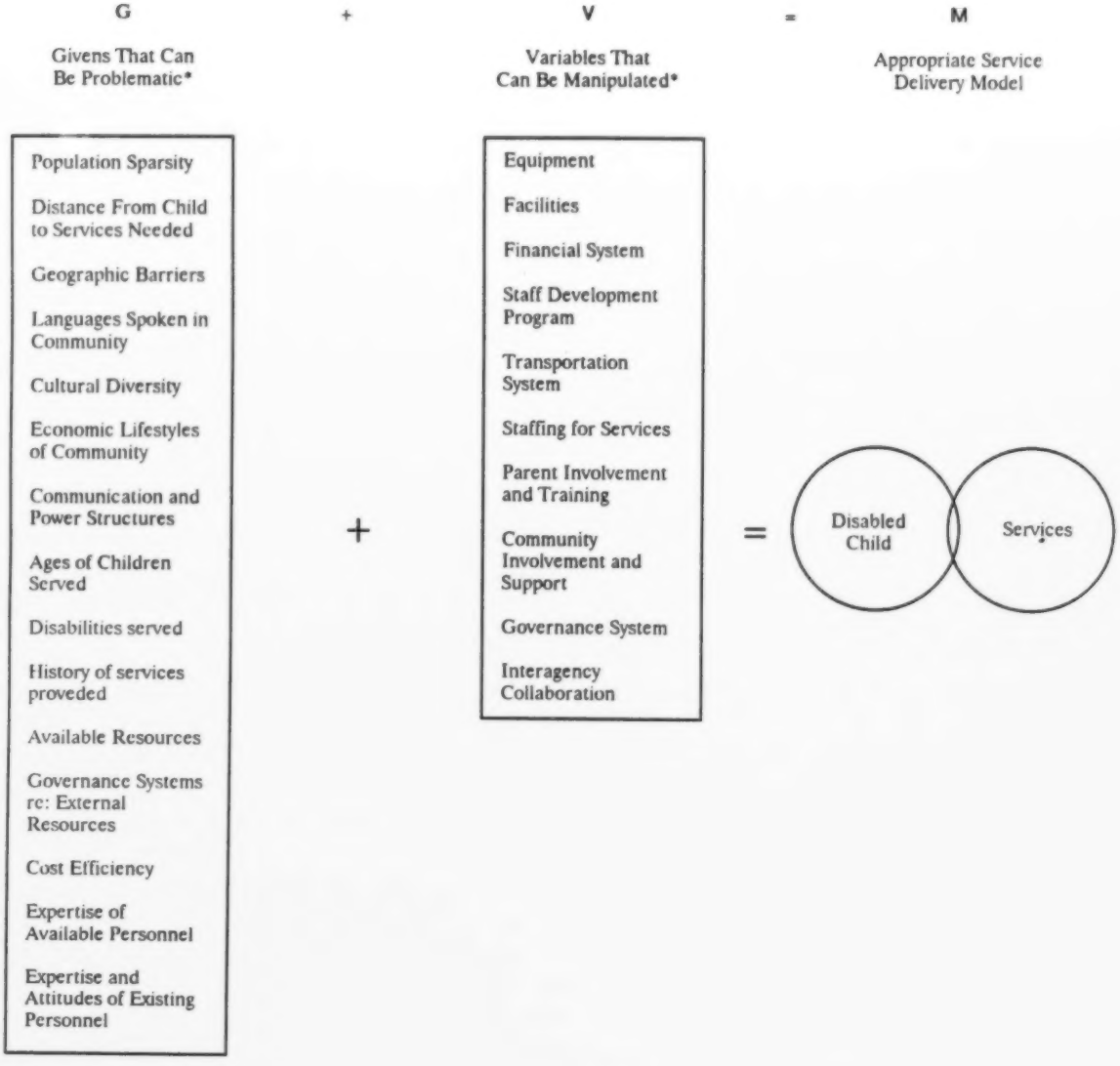


FIGURE 3.
Consideration of "givens" and manipulation of "variables" allows the planner to create an appropriate service model.



*Items italicized are illustrative.

Samples of Successful Service Delivery Models

The reader is reminded that low-incidence disabilities vary greatly from one area to the next because of population and environmental influences. Thus, in one area, a given model may be used to serve children who are cerebral palsied or deaf. In another very sparsely populated area, the model may be adapted to serve the only moderately retarded child in the community.

Development of each of the successful models and strategies described in this monograph involved the recognition of factors discussed in the section on considerations for service delivery planning. Each design highlights the manipulation of one or more of the ten variables listed, although none of the models or strategies controlled or changed all of them.

An adroit planner would not directly "transport" any of the sample models, but would consider them illustrative of the ways in which factors can be recognized and/or variables manipulated in order to create a subculture-specific model.

Programs Having a High Respect for the Unique Needs of Families

A. Project PPEP

Project PPEP, Inc., is an organization which provides a number of services throughout Arizona, including: crisis intervention counseling, food, clothing, and rent assistance, and a child abuse prevention program. Anyone who wishes to volunteer their services or is in need of help should contact: PPEP, 806 East 46th Street, Tucson, AZ 85713; 602/622-3553

B. Parent Pilot Program

The Parent Pilot Program is one in which parents of handicapped children help other parents who have recently learned that their child has a special need. The program's main purpose is to provide supportive, experienced parents to pilot "new parents" through the initial difficulties of accepting that their child is handicapped, learning about handicapping conditions, and finding the proper services to aid their child in his or her development. Contact services for this project are as follows:

Idaho Falls
Carma Mordecai
6827 Jennifer Lane
Idaho Falls, ID 83402
208/524-1619

Twin Falls
Debbie Johnson
809 East 18th
Jerome, ID 83338
208/324-5842

Boise

Linda Jensen
P.O. Box 1100
Boise, ID 83701
208/343-2583

Moscow

Kathy Salzwedel
603 W. Palouse River Dr.
Moscow, ID 83843
208/882-9049

Coeur d'Alene

Lori Hill
North 9735 Valleyway
Rathdrum, ID 83858
208/772-6209

C. Saratoga REACH

Saratoga REACH is a unique program in which Saratoga county families of handicapped children share child care with one another. Parents get more time to relax or catch up while their children are with families they have come to know and trust. Disabled children and their siblings meet new friends, and the care can be used short-term or in case of an emergency or family vacation. Saratoga REACH helps take the worry out of child care because parents train each other and exchange care with the support of professionals who understand special needs. To request information, brochures, or an application or program presentation for a family or group, call 518/584-5000, Ext. 2340.

Creating Responsive Communities for Rural Families. Opening Up Communities so that Community-Family Integration is Real.

A. Project PPEP (see above).

B. Parent to Parent of Snohomish County

Parent to Parent of Snohomish County has empathetic parents who have been trained to link with another parent with similar experiences. They are available to help parents through their time of need, whether it be diagnosis, hospitalization, ongoing care of their child, or just need of a friend. Call: Colleen Webb; 206/668-3275.

C. White Rock Delta Infant Development Program

This program serves infants ages 0-3. Staff persons work directly in the home of the family and offer resources to parents. The program services are all provided free of charge. Contact: White Rock Delta Infant Development Program, 1185 Centre Street, White Rock, BC B4B 4C8.

Building Parent/Professional Partnerships--Formalized Approaches including Training for Families and Professionals

A. ACRES National Rural Parent-Professional Consortium

The ACRES National Rural Parent Professional Consortium is an extremely effective working group of rural parents and professionals from across the United States and Canada. Products have included the ACRES Rural Parent Resource Directory developed and peer reviewed by rural parents. Contact: ACRES National Rural Parent Professional Consortium, Suzanne Ripley, NICHCY, 7926 Jones Branch Dr., McLean, VA 22102; 703/893-6061 or Audray Holm, 1750 E. Hill Rd., Willits, CA 95490; 707/459-4172.

B. Education Planning: Improving Communication (EPIC)

EPIC is a program that achieves more effective educational planning by improving the communication process between parents and professionals. A cost-effective team of both parents and professionals work together to evaluate and plan a program for the child. The program has been selected as a promising practice in special education by the Connecticut State Department of Education. Contact: Lois Rho, Cheshire Public Schools, Department of Education, 29 East Main Street, Cheshire, CT 06410.

C. White Rock Delta Infant Development Program (see above).

D. PARENTS (Parents Assisting Rural Educators through Networking and Teaching in Schools).

This parent-professional partnership is an effective model for parent involvement in rural schools. It is a Parent Liaison Program employed by the PARENTS project for increasing parent involvement and building parent-professional partnerships. The goals of the Parent Liaison Program are achieved through three major program components: a: home/school communication; b) parent participation; and c) parent collaboration. For further information, contact: Anita Hodges, Parent Coordinator, PARENTS Project, 300 Enola Road, Morgantown, NC 28655

Accessing Services

A. An example of accessing services in spite of geographic difficulties and cultural diversity follows. An audio conferencing system out of Juneau, Alaska, connects parents from across Alaska who then share a variety of resources for their children. For example, each time a child having two different sized feet needs a pair of shoes, parents who have been connected by this audio conferencing system know other parents who are willing to share shoes, saving both families money. Besides such physical and economic support, parents provide tremendous emotional support for one another. Contact: Linda Griffith, Project SEPTER, Southeast Regional Resource Center, 218 Front Street, Juneau, AK 99801; 907/586-6806.

B. Pilot Parent Program (see above).

Establishing Interagency Commitment and Eliminating Duplication and Fragmentation

A. Arlington Interagency Project

This project won an ACRES Exemplary Rural Special Education Award for its innovative approaches. It operates under the belief that for a program to be successful, the interagency group must go to families. They must help families focus on their strengths and develop a plan of action for themselves. Contact: Diane McCutchen, Project Coordinator, Arlington School District, 600 East Fir Street, Arlington, WA 98223; 206/435-2156.

B. The Home Activity Program for Parents and Youngsters (HAPPY)

This program addresses the needs of underserved young children with handicaps and their families who live in isolated rural areas of Nevada. This model program has two interrelated components: computer-assisted home-based curricula and video-assisted home-based assessment and instruction. This program is exceptionally strong in its parent/professional partnership aspect and in the delivery of home-based services.

Creating New Services. Taking What Exists and Shaping it into Something New

A. Project SHaRE (Sources of Help Received and Exchanged)

Project SHaRE is a family support program of the Family Infant and Preschool Program located in rural western North Carolina. SHaRE is using one of the oldest practices of helping families meet needs, called "reciprocity." Eighty families and individuals, half of whom are caring for a disabled family member in the home, have formed a unique community partnership that functions as an informal support network. SHaRE members have discovered that they have a wide variety of strengths, products and services, that they exchange with others in order to secure the goods, services, and products they in turn need. The SHaRE program could be easily replicated in other rural school districts by churches, parent groups, or civic clubs. Contact: Lynda L. Pletcher, Coordinator-Project SHaRE, Family Infant and Preschool Program, Morganton, NC.

B. Community-Business-School Partnerships

Rural school, community, and family programs are most successful when they form partnerships with businesses. The scarcity of rural resources simply requires collaboration. An example of identifying all potential local resource systems and using them to assist in programs is that students related to the Western Oregon State College rural special education training program routinely contact local businesses and unique agencies such as the local reform institutions to see how they may help in training efforts. Contact: Bonnie Young, Department of Special Education, Western Oregon State College, Monmouth, OR 503/838-1220, Ext. 322.

Strategies for Hard to Reach Families

A. Parents Lets Unite for Kids (PLUK)

The goals of this program are to provide an information network for parents, train parents to communicate more effectively with educational personnel, and to link parents of handicapped children with other special needs parents. They also provide parent training to meet the unique needs of Native American parents with special needs children. One way they accomplish this is to provide a minimum of two communication workshops designed specifically for Native American parents which they present on reservations each year.

Project Director: Katharin A. Kelker
Telephone: 406/657-2055
Address: PLUK
Box 30935
Billings, Montana

B. Parent Training and Information Center for Parents of Handicapped Children in Mississippi under P.L. 94-142.

This program provides individual assistance and training to parents of handicapped children in Mississippi. Within the scope of the program they recruit, identify, and train present facilitators to serve two underrepresented populations, the Mississippi's Band of Choctaw Indians and the Black Community of the Mississippi Delta Region. The role of parents who participate in workshops or individual assistance is to exercise their rights and

responsibilities in planning, monitoring, and implementing programs for their special needs children.

Project Director: Anne Presley
Phone: 601/922-3210
Address: Association of Developmental Organizations
of Mississippi, Inc.
6055 Highway 18 South
Jackson, MS 39212

C. Project SEPTER (Special Education Parent Team for Equal Rights)

This program provides a diversity of services to parents of handicapped children throughout the state of Alaska. Services include parent training workshops, a newsletter, audio conferences, a statewide equipment exchange, sibling workshops, a parent guide, and comprehensive parent training. This project emphasizes training parents to reach out into their communities and assist other parents with special needs children.

Contact: Linda Griffith
Special Education Consultant
Project SEPTER
218 Front Street
Juneau, AK

Strategies Involved in Successful Service Delivery Models

Using Non-School Personnel

Discussion/support groups led by parents are much more successful than those led by professionals. Rural programs frequently find that a public service announcement made by a parent stating that he is not affiliated with the agency and would like to visit with and possibly assist other parents, is particularly successful. The parent groups originally meet on their own and later can become an integral part of the agency's feedback system.

Messages can be sent to isolated rural communities via persons who frequent such areas on a regular basis (e.g., mail carriers, utility meter readers, bookmobile personnel, public health workers, and county extension workers).

School personnel should work cooperatively with other agencies who visit families or provide services to those with disabilities (e.g., home health agents or county demonstration workers).

Meetings can be arranged of parent groups with diverse foci to encourage them to share personal achievements/ideas and occasionally have joint projects. Joint advocacy projects are more effective than those of single parent groups.

Local physicians should be informed of which parents are willing to work with other parents who are just learning that their children have disabilities. It is extremely helpful for parents newly experiencing emotions such as shock, grief, and hostility, to have a parent near who understands these emotions. This is a particularly effective technique in rural areas where parents (and sometimes physicians) know which families have children with disabilities.

Local physicians should be educated regarding the needs of parents of disabled children and community resources that are available to them.

Family Involvement

The involvement of siblings and extended family members is an asset. This practice also frequently encourages reticent parents to become involved. Families should be involved in designing unique program strategies (e.g., rural orientation and mobility markers).

Social Ties

Rural parents are frequently reticent to become involved with the "authority figures" of the school regarding their child's program. Thus, it is essential that service providers and administrators establish a positive rapport with parents. This sometimes occures via a one-on-one discussion between service providers and parents regarding the strengths and weaknesses of the child's performance. It is frequently useful to precede such a discussion with social contacts. In fact, many rural districts host non-threatening social events or meetings preceded by a meal. Free babysitting is also an established part of such events in several rural areas. Such amenities increase parent willingness to share valuable information with agencies and to follow up educational instruction within the home setting.

Service providers who are respected community members have the most success with parents becoming actively involved with their program. Even itinerant staff who only visit a community once a month can express a sincere interest in community events and problems. This is especially true if they talk with the key communicators in the community (ranging from postal clerks and gas station attendants to school board members).

Home visits, after sufficient rapport has been established, are invaluable. Typically, itinerant staff, practicum students from regional universities, or others who accept invitations to visit or stay in children's homes while traveling learn a great deal about the real strengths and stresses of the family and generate the most success for the special needs program. Because of this, many programs plan for mobile instructional vans to travel through isolated regions. Generally, this also increases the commitment of the professional.

Meeting Other Family Needs

It is critical to truly listen to families and respond to their stated needs even if those are not on the professional's agenda (e.g., adult literacy, drug education for family members, etc.). Babysitting "checks" can be provided to parents for four to five hours of respite care. These can be donated by volunteers or by other parents of special needs children, establishing a parent-to-parent support system. It is especially helpful to establish one central location or phone number for parents to call for help and one community intake form for all agencies. Responsive service may include traveling clinics and/or a community focus which would bring a consultation team to a community office. Compliance tracking by agencies is also helpful to parents, particularly those who are confused or nervous about dealing with educational and service delivery systems. It is also helpful to define roles for professionals to take in helping parents with their financial problems.

Family support groups should have an understanding that starting small and being patient as the group grows through the grapevine will be a profitable long-term strategy.

Parents should be taught communication skills so that they may effectively and assertively present their needs to communities and other agencies and professionals. This is particularly true of parents who are of a different ethnic background, migrant parents, and/or those who are illiterate. This should be done, if possible, by a person who is from a similar background.

Identifying and Using Local Power and Communication Sources

Parents and professionals should look for natural resources in the community for communication, finances, transportation, and other resources. Informal community structures should be explored to find out who the community person or persons are that can get things done.

By nature, rural America is based on informal structures and natural communication systems. Such systems should be used to "spread the word." In locating power sources, it is critical to use the media for free public service announcements and to try to identify people "behind the power." This may be a spouse, a business or social colleague, a well-respected person who attends the local church or is a cooperative extension worker, the gas station attendant at the one regional gas station who therefore talks with everyone who comes through the community, etc. These people can be essential in gathering support for quality services for children. Such key communicators and power sources must be given opportunities to really get to know some of the children and families so that they can become advocates for the cause.

Regional and local corporations or outreach businesses should be approached for use of their equipment and staff, corporate donations, donations of equipment as they upgrade theirs, etc. Corporate tax deductions can be an incentive. Frequently, a more important incentive in rural areas is to let companies know that the informal grapevine will be used, as well as formal articles in the local newspaper speaking of how helpful they have been.

Bookmobiles, county extension workers, public health workers, meter readers, and other natural transporters and communicators can be an essential component of effective communication for a program.

Parents typically need a neutral place to meet, accessibility to meetings, practical information presented at the meeting (preferably by a parent), and assertiveness training regarding asking for help. Parents are also needed on agency boards for the important input that only they are capable of giving.

All possible community resources should be used, particularly those that are informal and involve excellent communicators. This may include the local Garden Club, the Grange, the Welcome Wagon, or, in larger communities, a Lion's Club. Churches and bars are generally also important communication institutions in rural areas.

Technology

Technological devices can be as simple as a CB radio (capable of serving several families in clustered rural areas) or a telephone answering machine. Answering machines offer parents options of listening, at their convenience, to student progress reports and appeals for instructional assistance at home.

Teaching materials to be taught by parents can be coordinated with television broadcasts or telecommunication systems and supplemented by mobile vans or itinerant staff visits.

Video or cassette tapes can be mailed to parents for instructional use, or educators for critique, regarding a child's progress. Teacher visits and/or counseling via telephone, audio conferencing, or teleconferencing can be supplemental.

Families should be encouraged to use the "Green Thumb Network" menu of CompuServe regarding potential services of county extension agencies. Parents with computers can take advantage of this service.

Parent/Community Communications

"Communication books," designed by teachers, can be sent home with children on a daily or periodic basis. Such books offer advice for at home follow-up reports of progress, etc., and can be responded to by parents.

School newsletters (even a one-page mimeographed sheet) should contain articles or suggestions made by parents and a recognition that parent support is crucial for effective parenting.

ACRES Rural Parent Consortium

The ACRES Rural Parent Consortium links parents and professionals with services that may be of help to them. The consortium enhances rural family-professional involvement and links families of rural handicapped children with valuable resources and information. A Rural Parent Resource Directory was developed by the consortium and is available from ACRES headquarters. (American Council on Rural Special Education, Western Washington University, Bellingham, Washington; 206/676-3576). The Consortium is also collecting information on existing fathers' support groups and resources, collects information on available resources and strategies for ethnic minorities and other culturally diverse groups, and reviews and evaluates university course work that concerns rural families of handicapped children.

The Parent Consortium meets each year at the ACRES National Rural Special Education Conference.

Curriculum for Physicians Defining Their Role with Parents of Handicapped Children

The American Academy of Pediatrics, during 1982-84, developed a model 16-hour training curriculum for practicing physicians. The curriculum underscored the physician's multiple roles as medical caregiver to the child, counselor to the child and parents, and consultant to community agencies and schools, as an advocate and a concerned professional. The curriculum is available through the American Academy of Pediatrics headquartered in Evanston, Illinois.

professional. The curriculum is available through the American Academy of Pediatrics headquartered in Evanston, Illinois.

Other Samples of Successful Service Delivery Models

State-Funded Intermediate Education Units (IEUs)

This administrative structure uses regional specialists who provide technical assistance and consultation to local district personnel. Some IEUs are designed specifically to provide special education services and others are designed to provide all specialized services that are difficult for small school districts to provide (e.g., comprehensive vocational education). IEU personnel generally provide services only to other professionals. This pattern is sometimes varied to demonstrate an effective technique or to train a professional to deliver the service independently in the future.

Some IEUs have centralized media and materials centers with extensive options for parent check-out, and some states incorporate mobile material centers. Generic specialists at the local level are sometimes supported by specialized regional consultants dealing with specific types of disabilities. This type of model is responsive to rural remote areas when consultant responsibilities are aligned by geographic region vs. an entire state. The planner adapting this model for a particular area would want to design safeguards to that a generic specialist did not become too dependent on a regional specialist. This would prevent inadequate services or a lack of services in the absence of the regional specialist.

Statewide Networks of Itinerant Specialists

The small, rural state of New Hampshire has implemented a system to serve students with the low-incidence handicaps of hearing and visual impairments. This system is operated by contract with a private firm that hires consultants to provide services to blind and deaf students in remote rural areas with no specialized local personnel. These consultants also train local personnel to deliver follow-up services until they return. Items from an extensive media and materials center are taken to the local program for use when

the consultants are absent, and are varied and updated as needed. This is an important resource for rural parents.

Model to Identify Scarce Resources

Other isolated rural areas have identified and optimally used every possible resource within their community. They have found that using community personnel as resources has created a side benefit of additional community support for their program.

Although the model varies from community to community, the following basic components are consistently present:

* Completion of a needs assessment at the total program level, as well as in each individual classroom or therapy center.

* Completion of a resource survey of all program personnel, listing skills and competencies that could be shared with others, including children with low-incidence handicaps. Data on potential community and parent resources are an integral part of the resource base. Community facilities and equipment are included in the resource data bank.

* Use of a manual card-sorting or a computerized retrieval system to link identified resources and needs. This linkage may include having one service provider, uncomfortable working with a child with a hearing impairment, view another service provider with skills in this area. It may also include using older students (e.g., high school students in a child development class), as "extra manpower" by having them assist a service provider with follow up motor skills activities for children with severe physical impairments. Other programs have used unemployed certified personnel, retired personnel, and other community members as volunteers in the classroom or therapy center. Isolated resort communities have actively recruited the assistance of long-term visitors. Volunteers provide services ranging from tutoring children to furnishing transportation. They reduce staff development costs by managing a program while a service provider engages in inservice, peer observation, or other relevant activities.

The legalities and protocol of each of these models are individualized for the particular area in which the model is incorporated. However, in all cases, an evolving foundation of community resources is established. Community support for the program is enhanced in each location because citizens become integrally involved in programming.

Models Incorporating Advanced Technologies

The use of advanced technologies as a tool for serving remotely located children with disabilities is rapidly growing in popularity. For example, a variety of systems has

been used to send instructions to isolated service providers inadequately trained to work with children with low-incidence handicaps. Model design ranges from consultant-teacher communication by satellite to remote inservice vans bearing computers programmed to teach specific subject areas to parents or children. Less expensive models include exchanges of video tapes and one/two-way television instruction.

Technological approaches will be limited more by the imagination of the service planner than by the cost of equipment. Alternate types of advanced technologies are becoming increasingly available in agencies external to schools. Many programs have found human service agencies willing to collaborate in service delivery, especially when highly specialized equipment is not used by the agency on a full-time basis. Likewise, many rural businesses have been willing to share equipment. Adept administrators have been able to borrow by emphasizing advantages to local businesses, such as enhancement of their community image and potential tax write-offs.

Models Using Paraprofessionals

Trained paraprofessionals are frequently used by rural programs when certified personnel are unavailable. Paraprofessionals support certified staff conducting classroom or therapy activities with handicapped children. Tutoring activities might range from academic or psychomotor curriculum activities to counseling regarding improvement of social skills or work with parents. Paraprofessionals might also conduct follow-through exercises assigned by a speech, physical, or occupational therapist or assist with adaptive physical education exercises.

An essential ingredient in the effective design of a paraprofessional model is appropriate training and careful observation of performance. Trained paraprofessionals are frequently teamed with parent and community volunteers. Paraprofessional personnel are usually paid staff members, although there have been instances in which they functioned on a volunteer basis. Most rural paraprofessional programs have assumed that paraprofessionals will function as generalists. Their specialized tasks are generally limited

to supervised follow-through activities assigned by speech, occupational, or physical therapists.

Summary

Traditional models and strategies designed to provide a continuum of services to handicapped children are inadequate for rural areas. The uniqueness of the rural community context requires service delivery strategies and models distinctly different from those of nonrural areas. Family involvement and interagency collaboration are essential for successful service delivery. Because of the tremendous diversity in rural areas, there is no "one" rural service delivery model. There are, however, a number of community and agency characteristics that a model designer must consider. The planner may then appropriately control variables such as usage of personnel, transportation systems, and parent, extended family, and other community involvement to design an individualized model viable for the child, parents, community, and service agencies, including schools.

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